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## Plan Overview

*A Data Management Plan created using DMPTuuli*

**Title:** Psychosocial and Spiritual Needs of Children with Terminal Cancer and Their Families: A Comparative Study of Social Work Responses in China and Finland

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**Template:** General Finnish DMP template

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### Project abstract:

Psychosocial and spiritual support is a core component of pediatric palliative care. In Mainland China, pediatric palliative care and social work practice are still in the early stages of development, leading to the neglect of psychosocial and spiritual needs. In contrast, Finland has established a more comprehensive system and practice framework in this field.

This study aims to explore the psychosocial and spiritual needs of children with terminal cancer and their families in Mainland China, and to analyze the roles and challenges of current social work practices in addressing these needs. Through a comparative study with Finland's well-developed social work practices, the research seeks to identify culturally adaptable and applicable approaches to promote the development of a more empathetic, systematic, and professionally supported pediatric palliative social work model in the Chinese context, providing more holistic and dignified end-of-life care for children and their families.

A qualitative research design will be employed, combining descriptive and comparative methods. Semi-structured interviews and document analysis will be conducted with caregivers, social workers, and professionals from Finland to collect diverse perspectives, with thematic analysis used for cross-cultural comparison and synthesis.

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# Psychosocial and Spiritual Needs of Children with Terminal Cancer and Their Families: A Comparative Study of Social Work Responses in China and Finland

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## 1. General description of the data

**1.1 What kinds of data is your research based on? What data will be collected, produced or reused? What file formats will the data be in? Additionally, give a rough estimate of the size of the data produced/collected.**

The research data will be based on both primary and secondary data sources. Primary data will be gathered through semi-structured interviews, focus group discussions (FGDs), and observation. Secondary data will be gathered from documents of social workers, journal articles, published and unpublished theses and books, policy papers, print and electronic media, and internet sources. Under primary data sources, semi-structured interviews will be conducted in Chongqing, Beijing and Helsinki areas, to gain in-depth insights into the role of social workers in pediatric palliative care. In addition, semi-structured interviews will be conducted in Chongqing and Beijing with families of palliative children to gain a deeper understanding of the psychosocial and spiritual needs of both the children and their families when facing end-of-life situations. The interviews will help to gather varied but relevant perspectives on the subject matter. Meanwhile, participants will be drawn from family members of end-of-life children from 2-3 hospitals for the interviews. Data gathered will be stored using common file types that allow for open data formats such as docx, pdf, excel, mp3, mp4, and txt. The size of the data (e.g., recorded audio/videos) is expected not to be more than 3 GB.

## 1.2 How will the consistency and quality of data be controlled?

For data collection from families of pediatric patients, data source triangulation will be employed by gathering information from different times, locations, and individuals. In addition, methodological triangulation will be applied by using observations, interviews, and document analysis. For the data related to social workers, information will be collected through both focus groups and individual interviews, as well as from various hospitals and professional roles, to ensure the consistency and quality of the data gathered. Since the researcher speaks and understands the Sichuanese mandarin and Chinese languages of Chongqing and Beijing, respectively, communication and information gathering will be effective and ensure the consistency of data. The interviews conducted in the Finland region will primarily be carried out in English, with Finnish-English translation provided as needed. What's more, transcripts from audio interviews will undergo a double check with notes taken during the interviews and with external actors (e.g., faculty members and colleagues) to ensure consistency and accuracy of information obtained.

| Data  | Is the data collected, produced, or reused | File format                 | File size | Sensitive data(Y/N) | What part of the data can be made openly available       | Who owns the data/planned licenses   |
|---|--|-----------------------------|-----------|---------------------|--|--|
| Primary data: Interviews  | To be collected                            | Docx, txt, mp3, and mp4     | 0.5 GB    | Yes                 | Metadata- that will not expose the participant to danger | The Ph.D. researcher   |
| Focus group discussion  | To be collected                            | Docx, txt, mp3, and mp4     | 0.5 GB    | Yes                 | Metadata- that will not expose the participant to danger | The Ph.D. researcher   |
| Observation   | To be collected                            | Mp4/video, audio recordings | 0.5 GB    | Yes                 | Metadata- that will not expose the participant to danger | The Ph.D. researcher   |
| Secondary data: documents from social worker  | To be collected                            | Docx, excel, pdf            | 0.5 GB    | Yes                 | Metadata- that will not expose the participant to danger | Social workers own the data. But adapted data owned by the Ph.D researcher                             |
| Secondary data: Journal articles, published and unpublished theses and books, policy papers, print and electronic media, and internet sources | To be re-used                              | txt, online                 | 0.5 GB    | No                  | Metadata- that will not expose the participant to danger | The original authors and agencies own the data. But adapted data will be owned by the Ph.D. researcher |

## 2. Ethical and legal compliance

### 2.1 What legal issues are related to your data management? (For example, GDPR and other legislation affecting data processing.)

This study involves human participants and may address sensitive topics, especially for participants from families. As such, ethical responsibility and adherence to legal regulations are essential for safeguarding participants' privacy and ensuring the integrity of the research. Ethical principles, including the commitment to "do not harm," will be upheld through compliance with the General Data Protection Regulation (GDPR) and approval from the relevant faculty and ethics committee. The research will be guided by principles such as transparency, informed consent, voluntary participation, confidentiality, anonymity, reflexivity, and critical distance. Any information that may pose a risk to participants will be anonymized, renamed, or deleted after its use to protect their identity.

### 2.2 How will you manage the rights of the data you use, produce and share?

The doctoral researcher will retain sole ownership of the research data and will share it with their supervisor(s) throughout the entire research process. Upon completion of the project, non-sensitive data will be made openly accessible to the research community, policymakers, and government agencies through academic journals, publications, and online platforms. Any reuse of the research data should be properly acknowledged and cited by those seeking to contribute to the understanding of sustainability transitions, natural resource governance, and sustainable development policies, particularly in the areas of land use and conflict resolution at local, national, and global levels.

### 3. Documentation and metadata

#### 3.1 How will you document your data in order to make it findable, accessible, interoperable and re-usable for you and others? What kind of metadata standards, README files or other documentation will you use to help others to understand and use your data?

To ensure that the research data is findable, accessible, interoperable, and reusable (FAIR), all non-sensitive data will be documented systematically and made openly accessible. Comprehensive metadata—including administrative, structural, and descriptive metadata—will accompany the datasets to enhance discoverability and usability. The study will adopt the Data Documentation Initiative (DDI) metadata standard, which is well-suited for documenting social science and qualitative data.

In addition, each dataset will be accompanied by README files that clearly describe the data structure, variables, collection methods, context of the study, and any relevant codes or classifications used. These files will also outline any limitations or considerations for secondary use. This documentation will help ensure that other researchers, policymakers, and stakeholders can understand, evaluate, and responsibly reuse the data in ways that contribute to knowledge on sustainability transitions, land use, and conflict resolution.

### 4. Storage and backup during the research project

#### 4.1 Where will your data be stored, and how will the data be backed up?

A key component of field research is the secure storage and reliable backup of data. In this study, sensitive data and materials will be stored in electronic formats on password-protected devices to uphold principles of privacy and data security. Materials that do not pose risks to participants will be stored in personal or home archives, university libraries, or public archival departments to enable broader accessibility.

For backup purposes, data will be stored in the secure research storage space provided by the University of Eastern Finland (UEF). Audio recordings of interviews that may endanger participants will be deleted after transcription, and when necessary, transcripts will be pseudonymized immediately to protect participants' identities.

Upon completion of the research project, the finalized data will be deposited in the Finnish Social Science Data Archive (FSD) to ensure long-term preservation and public accessibility, in accordance with ethical and legal standards.

#### 4.2 Who will be responsible for controlling access to your data, and how will secured access be controlled?

The Ph.D. researcher will serve as the primary data controller and will determine access rights in accordance with privacy, protection, and safety considerations. The research supervisor(s) will have access to the data based on their academic supervisory role and established relationship of trust. Secondary access may be granted to collaborating researchers who are directly involved in the project, provided that such access aligns with the study's ethical and data protection protocols.

### 5. Opening, publishing and archiving the data after the research project

#### 5.1 What part of the data can be made openly available or published? Where and when will the data, or its metadata, be made available?

With the exception of data that may pose risks to research participants, all other data—including metadata—will be made publishable and accessible through relevant academic journals and the University of Eastern Finland (UEF) research platforms. Sensitive data and materials will be made available upon request, subject to careful ethical review and consideration. As the research project follows an article-based format, data sharing and publication will occur progressively, aligned with the timeline and development of each research article.

#### 5.2 Where will data with long-term value be preserved, and for how long?

To support knowledge advancement and enable future data reuse, the research data will be securely stored for the long term—potentially for several decades—at the Finnish Social Science Data Archive (FSD) and/or within the University of Eastern Finland's (UEF) secure research storage systems.

### 6. Data management responsibilities and resources

**6.1 Who (for example role, position, and institution) will be responsible for data management?**

Both the Ph.D. researcher and the University of Eastern Finland (UEF) will be responsible for data management. The Ph.D. researcher, as the primary investigator, will oversee the day-to-day handling, organization, and ethical use of the data throughout the project. The University of Eastern Finland will provide institutional support by ensuring access to secure storage infrastructure, data protection compliance, and long-term archiving services.

**6.2 What resources will be required for your data management procedures to ensure that the data can be opened and preserved according to FAIR principles (Findable, Accessible, Interoperable, Re-usable)?**

To ensure that the data management procedures align with the FAIR principles, the research project will utilize Fairdata services provided by the Ministry of Education and Culture in Finland (OKM/Minedu) and operated by CSC – IT Center for Science. These free national services offer tools for metadata creation, secure storage, and long-term preservation, making them essential for maintaining the accessibility and reusability of the data over time. No additional external resources are anticipated, as the existing institutional infrastructure (UEF) and Fairdata platform are expected to meet the project's data management needs.